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Disability, Care, and the City

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Introduction

This paper looks at the different ways in which disability is defined and understood, as a basis to explore the experience of disability in urban areas. It then discusses the significance of caring processes for Persons with Disabilities (PWD), as well as for people in relationships of care with PWD. It considers the political resonance of a focus on care for PWD, and how care relates to PWDs' other claims around independence and political voice.

These discussions are used a basis to explore the potential roles of Local and Regional Governments (LRGs) for creating caring environments, and supporting care relations with PWD in cities, looking at three entry points: supporting (paid and unpaid) care

work; ensuring the accessibility of infrastructures of care; and supporting the rights to care for PWD in contexts of informality. **Cutting across these three entry-points is the principle that PWD should lead in processes of decision-making and urban strategy development concerning disability inclusive cities.**

The paper is illustrated using material from a variety of sources, including the AT2030[1] research project on *Assistive Technologies (AT) in Informal Settlements in Sierra Leone and Indonesia,* which worked with PWD and AT users living in informal settlements in Freetown, Sierra Leone, and Banjarmasin, Indonesia.

1. Defining disability

While there are many competing definitions of disability, the United Nations Convention on the Rights of Persons with Disabilities (CRPD article 5) can be seen as the global standard, and this understands disability as "the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others". A similar approach was taken in the World Report on Disability which draws on a 'bio-psychosocial model' which "understands disability as dynamic integration between health conditions, contextual factors, both personal and environmental".[2]

This approach to disability builds on the learnings of the 'social' model of disability, which arose as a critique of the treatment of disability as a purely medical condition and its consequent equation with impairments, which thereby saw disability as a biological feature of the person.[3] In contrast, the social model argues that "disability is the outcome of an oppressive relationship between people with impairments and the rest of society".[4] The bio-psycho-social model however, attempts to build on the learnings of the social model but at the same time

to better recognise the embodied and psychological aspects of disability (i.e., the importance of impairment in PWD's lives, such as needs for rehabilitation or treatment for pain) which the social model, for political reasons, has avoided. Such an understanding, encompassing both disabling social processes, and the lived reality of impairments, underpins both WHO definition of disability as well as that used in the Convention on the Rights of Persons with Disabilities (CRPD).[5]

While theoretical approaches to disability are increasingly nuanced in addressing the complexity of disability as a parameter of social identity,[6] the treatment of disability in practical interventions is often more black and white. For example, social policy frequently uses cut-off criteria for rights to disability related social protection, often based on medical assessment, and thereby presents it as a binary: disabled vs. non-disabled. This approach to disability is problematic in failing to recognise that people experience disability in complex, person specific, and relational ways. Disability can be permanent or temporary.[7] People's experience of disability normally varies over time (for example with ageing, or with some

1. A research programme which aims to support access to life-changing Assistive Technology (AT) at scale, and is funded by the UK Department for International Development (DFID) and delivered by the Global Disability Innovation Hub (GDI Hub).

2. World Health Organization, 2011. *World Report on Disability 2011*: 4.

3. C. Barnes, 2000. A Working Social Model? Disability, Work and Disability Politics in the 21st Century, *Critical Social Policy*, 20(4), 441-457.

4. V. Finkelstein, 1980, *Attitudes and disabled people: issues for discussion* (New York, World Rehabilitation Fund): 47.

5. CRPD (article 1) "Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others."

6. T. Shakespeare, 2014, *Disability Rights and Wrongs Revisited*, (Routledge).

7. World Health Organization, 2011. *World Report on Disability 2011*.

people moving in and out of disabilities, such as those related to mental health or illnesses such as cancer), and is context specific, as "'disability' may mean radically different things in different cultures".[8] Linked to this is the importance of who defines disability – PWD themselves, or medical experts. This conflict has been evident in debates between Organisations of Persons with Disabilities and the World Health Organization in relation to the latter's promotion of the International Classification of Impairments, Disabilities and Handicaps, which many OPDs feel uses medical 'objective' criteria for disability which undermine the principles of the social model of disability.[9]

Furthermore, in terms of the self-definition of individual PWD, while tools such as the Washington Group Questions be used to assess respondents' evaluation of the level of functional difficulties that they face across six domains such as vision, hearing, or mobility, as a basis to generate data on disability prevalence[10] people with high levels of functioning difficulties may not self-identify as disabled. For example, in a context that disability is culturally and institutionally approached as distinct from old age,[11] older people with functional impairments can be less likely to regard themselves as disabled.

In addition, when we consider that a key component of disability as defined by the CRPD is the result of social norms and practices of exclusion, (how) can the disabling treatment of impairment be disentangled from exclusions based on people's other social identities, such as their gender, religion, age, or sexuality?[12] In this vein, authors such as Mitra contend that "An individual is disabled if he or she cannot do or be the things he or she values doing or being"[13] which blurs the lines between disability linked to impairments and to other factors of exclusion. **Treating disability as part of the wider spectrum of social exclusion and inclusion in this way has the appeal of recognising the complex reality of disability, and of not casting disabled people 'other'.**

However, at the same time as emphasising the complexity and subjectivity of disability as an identity, there is an important political function

of recognising PWD as a distinctive group, which requires some marker of who is, and who is not, a PWD. This is crucial as a basis for the political mobilization of PWD in a disability movement, based on, for example, the adoption of disability as a positive, politicised identity,[14] and the mobilisation of OPDs as political interest groups. Thus for example, Clifford, talking about the work of the OPD Disabled People Against Cuts (DPAC) in the United Kingdom highlights the importance of PWD coming together as a distinctive group negotiating on behalf of a shared set of disability related claims.[15]

Demarcating disability as a clear category is also a necessary precondition for research and data collection, which is crucial as a means of identifying patterns of inequality linked to disability as a basis for advocacy. However, in practice, the lack of clarity of definition and visibility of PWD is a barrier to such data collection: "Disability questions often are not included in censuses and surveys, or the statistics collected are inaccurate because of poor clarity of definitions or stigma that makes respondents reluctant to identify themselves or household members as disabled."[16]

Given these contradictory imperatives, definitions of disability need to straddle the importance of, on the one hand, clearly revealing, through research, pervasive inequalities faced by PWD, and demarcating disability as basis for a visible and politicised social identity, at the same time as avoiding, on the other hand, the reification of disability as an often externally imposed and stigmatising label, and eliding the shared experiences of exclusion which can act as a basis for solidarity between PWD and non-disabled people.

8. J.E. Bickenbach, 2009. Disability, culture and the UN convention. *Disability and Rehabilitation*, 31(14): 1112.

9. M. Oliver, 2017, Defining impairment and disability. *Disability and Equality Law*, 3.

10. N.E. Groce & D. Mont, 2017, Counting disability: emerging consensus on the Washington Group questionnaire. *The Lancet Global Health*, 5(7), e649-e650.

11. H. Jönson & A.T. Larsson, 2009, The exclusion of older people in disability activism and policies—A case of inadvertent ageism? *Journal of Aging Studies*, 23(1), 69-77.

12. J. Walker et al, 2013, Gender, difference and urban change: Implications for the promotion of well-being? *Environment and Urbanization*, 25(1), 111–124.

13. S. Mitra, 2006, The Capability Approach and Disability. *Journal of Disability Policy Studies*, 16(4): 241.

14. S. Peters et al, 2009, Resistance, transformation and the politics of hope: Imagining a way forward for the disabled people's movement. *Disability & Society*, 24(5), 543-556.

15. E. Clifford, 2020, Inclusion London. In Julian Walker, Marcos Bau Carvalho and Ilinca Diaconescu (eds), *Urban Claims and the Right to the City: Grassroots Perspectives from London and Salvador da Bahia* (pp. 68–73). London: UCL Press.

16. Groce & Mont, 2017, "Counting disability," e649.

2. Disability and Caring

Promoting *care* in relation to disability is a critical goal, but one which can be in tension with other goals for PWD – specifically those related to autonomy, and independence. This apparent conflict is visible in both the academic literature, and the claims of the disability movement, the impact of which is evident in key public policies.

While the CRPD does not refer specifically to *care* as a right for PWD, it engages indirectly with the importance of care for realising other rights – for example, making reference to individuals' duties to each other and their communities, and to the need to "enable families to contribute towards the full and equal enjoyment of the rights of persons with disabilities" (Preamble, x) as well as making repeated reference to state duties to making reasonable accommodation, part of which has often been implement in practice through provision of personal care attendants . In contrast, promoting the *agency* and *autonomy* of PWD, is a far more explicit goal of the CRPD which refers to "individual autonomy and independence" (Preamble, n) and the need for PWD to be "actively involved in decision-making processes" (Preamble, o). At the urban scale, the Global Compact on Cities for All similarly calls to "Enable all persons to live independently and take appropriate measures in cities and human settlements that facilitate access, elimination of barriers and full participation of persons with disabilities and older persons" (para 2) and also focuses on the participation of PWD (para 3). While it makes no specific reference to care or carers it does, like the CRPD, promote reasonable accommodation.

This relative emphasis on autonomy and agency, rather than care, is rooted in the campaigns of OPD, and can be linked to an understandable discomfort with the history of approaches to care for PWD. Given that there is often a power asymmetry between care givers and care receivers,[17] "the concept of 'care' has been fraught with negative connotations within the disability movement, where it has been associated with dependence,

segregation and the infantilisation of disabled people" and the movement has had, instead, a primary focus on alternative goals related to empowerment, choice, and control often under the banner of independent living.[18]

However, while recognising its importance, other authors have expressed a concern with the ways that a focus on independence as a central focus of rights claims by PWD can play out. Firstly, it has been argued that this may have different consequences in different cultural contexts. While a focus on independence is a recognised route to social rights in more individualistic societies, in more collectivist cultural contexts, a strong emphasis on "...independence or autonomy may actually deprive the individual of their social role and lower their social standing and even quality of life."[19]

Secondly, authors exploring the tensions between care and autonomy have expressed a concern at the ways in which the focus on PWDs' right to autonomy and independence has been co-opted, whereby "the disabled people's movement's concept of independent living has been overshadowed by the use of the word 'independent' by those articulating a political vision which assumes that paid employment is the gate through which we all have to pass in order to achieve true 'independence"[20] with an associated danger that autonomy is conflated with individual responsibility and a reduce role for the state.

In the United Kingdom, for example, cuts to disability benefits and a reduction in the number of PWD who are successful in securing disability benefits have been associated with the transition from Disability Living Allowance to Personal Independence Payment as key social protection instruments for PWD.[21] These policy changes are explicitly designed to promote fiscal austerity by rendering many PWD ineligible for benefits, but have been justified by government actors promoting them using the disability movement's own language

17. J.C. Tronto, 1998,. An ethic of care. *Generations: Journal of the American Society on Aging*, 22(3), 15-20.

18. A. Scott & C. Doughty, 2012, Care, empowerment and self-determination in the practice of peer support. *Disability & Society*, 27(7): 1012.

19. V.S. Pineda, 2020. What Makes a City Accessible and Inclusive?. *In Building the Inclusive City* (Palgrave Pivot, Cham): 52.

20. J. Morris, 2011, *Rethinking disability policy: Viewpoint* (York: Joseph Rowntree Foundation): 11.

21. R. Machin, 2017, Made to measure? An analysis of the transition from Disability Living Allowance to Personal Independence Payment. *Journal of Social Welfare and Family Law*, 39(4), 435-453.

of 'independence'. This link has been made through arguing that PWD should be weaned off 'welfare dependency' and incentivised to be independent through going to work, in the context of a new disability assessment system that is more likely underestimate the limitations in the ability to work resulting from applicants' impairments.[22] **Furthermore, this interpretation of independence as self-sufficiency has had the result of increasing stigma associated with PWD by casting many of those who are unable to work as 'scroungers and shirkers'.[23]**

The negative results of such policies, which led to cuts in care services while using the language of independence, have been highlighted by organizations such as the UK Disabled Peoples' Organization (DPO), 'Disabled People Against Cuts' (DPAC), which challenges the impact such austerity related cuts to care services on the well-being of PWD, including their urban, spatial dimensions. Ellen Clifford, a member of DPAC, highlights that "One of the impacts of the cuts is that people are trapped in their own homes, which makes them even more invisible, creates segregated communities."[24]

In parallel to free-market policies in contexts such as the United Kingdom have undermining existing care services for PWD, lack of care for PWD is also a pressing issue in many context in the Global South. For example, a survey of 2,152 people aged over 65 in Nigeria found that there is no formal care provision for older PWD living in the community and that "of the 263 persons who were classified as having any disability, 52 (19.8%) did not have a caregiver to help in areas of limitation."[25]

While there are few specific disability targeted social protection schemes outside high income countries, with some exceptions (e.g., South Africa and Fiji) many social protection schemes include disability as an eligibility criterion. However, social protection as vehicle for support for PWD focuses more on addressing poverty than ensuring the provision of care, whereas "If the focus is only on cash transfers, the lack of adequate healthcare, education, employment and other services combined with additional costs related to disability entrenches chronic poverty in households that have a member with disability."[26]
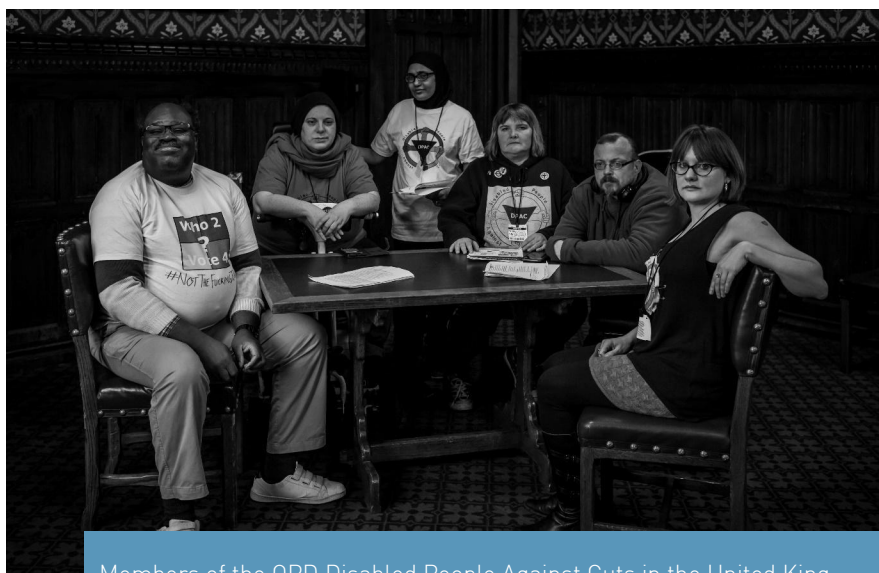
Members of the OPD Disabled People Against Cuts in the United Kingdom Houses of Parliament, where they mobilise to challenge cuts in disability benefits (Source: Angus Stewart)

Responding to a lack of care for PWD, and the ways in which a focus on independence has been used in some contexts as a justification for cutting budgets and interventions for care, a range of authors have emphasised the importance of approaching care for and independence and autonomy of PWD as mutually supporting, rather than as contradictory goals.[27] This thinking draws on a feminist ethics of care which emphasises *interdependence* rather than *independence*, and emphasises that care should be defined in emancipatory terms, by requiring that it meets criteria of attentiveness, responsibility, competence and responsiveness.[28]

Such an ethics of care, "demands that interdependence be seen as the basis of human interaction; in these terms, autonomy and independence are about the capacity for self-determination rather than the expectation of individual self-sufficiency."[29] Applied to relations of care for PWD, this implies "that disabled people should have choice and control over how any assistance they might need is provided – in order to enable autonomy and self-determination".[30] **At the same time, while care for PWD should be supportive of the autonomy of PWD, care as a relationship of interdependence also serves other important functions.** As Shakespeare notes, the focus in the United Kingdom social care system on providing personal assistance for PWD frequently emphasises personal assistants' role in ensuring the independence/ autonomy of disabled people while under-emphasising the emotional relationship between carers and disabled people which is also crucial.[31]

22. A. Roulstone, 2015, Personal Independence Payments, welfare reform and the shrinking disability category. *Disability & Society*, 30(5), 673-688.

23. K. Garthwaite, 2011. 'The Language of Shirkers and Scroungers?' Talking about Illness, Disability and Coalition Welfare Reform. *Disability & Society* 26 (3): 369–372.

24. Clifford, 2020, "Inclusion London," 73.

25. O, Gureje ET AL, 2006, Functional disability in elderly Nigerians: Results from the Ibadan Study of Aging. *Journal of the American Geriatrics Society*, 54(11): 1787.

26. M. Schneider et al, 2016, Social protection, chronic poverty and disability: Applying an intersectionality perspective. In Grech, S., & Soldatic, K. (Eds) *Disability in the Global South* (Springer, Cham): 371.

27. Scott & Doughty, 2012, "Care, empowerment and self-determination in the practice of peer support"; Morris, 2011, "*Rethinking disability policy.*"

28. Tronto, 1998, "An ethic of care."

29. F. Williams, 2001, In and beyond New Labour: towards a new political ethics of care. *Critical social policy*, 21(4): 487.

30. Morris, 2011, "*Rethinking disability policy,*" 11.

31. Shakespeare, 2014, "*Disability Rights and Wrongs Revisited.*"

Another important set of critiques around the treatment of care has also derived from feminist thinkers, and relates specifically to the impact on carers. This literature explores the ways in which care work has both been feminised,[32] and at the same time been undervalued, through the invisibility of time burdens for carers,[33] the failure to recognise the crucial role of care in social production and the economy,[34] and the fact that much household based care work is unpaid, or, in the case of domestic workers, underpaid.[35] **Another key question for the care for PWD therefore is how care work can properly be valued as a either an unpaid social role, or as a paid profession.** Giving such as value to care is necessary if it is to satisfy criteria for quality care, such as Tronto's attentiveness, responsibility, competence and responsiveness and thus provide respectful and emancipatory relations of care.[36]

Building on these discussions, this paper argues that **caring cities for PWD should (a) promote the importance of an emancipatory model of care which also supports the autonomy and self-determination of PWD, (b) emphasise interdependence rather only focusing on independence, (c) recognise the importance of emotional and relational aspects of care, and (d) ascribe proper value to the social and economic functions of care and care workers.**

3. Disability and Cities

Research has demonstrated that disability prevalence tends to be lower in urban areas than in rural areas. The Global Report on Disability surveying disability across 59 countries found a prevalence of 'significant difficulties' of 14.6 per cent in urban areas vs 16.4 in rural areas (and in low income countries this rises to 16.5 per cent in urban areas vs 18.6 per cent in rural areas).[37] This higher rural prevalence of disability is confirmed by more detailed surveys in specific country level studies, for example in the United States, China, or India.[38]

According to national censuses, this trend also applies to Indonesia and Sierra Leone, the case study countries for the AT2030 project. Wider research suggests that one reason for the higher prevalence of disability in rural areas may be linked to their association with older populations, who are more likely to experience functional impairments associated with ageing.[39] In the case of AT2030, respondents from OPDs involved in the study into informal markets for AT in Sierra Leone suggested as an additional explanation that the higher prevalence of disability in rural areas is linked to the limited possibilities for young PWD from rural areas to undertake job seeking migration to urban centres, as many of their peers do.[40]

As such, **the lower disability in urban areas may be seen as a problem rather than a positive association, if it is manifestation of the limited opportunities of PWD to migrate to urban or live in urban areas.** This seems to be supported by research which has revealed the ways in which the spatial development of cities reflects social processes of inequality and exclusion which disadvantage PWD in a range of different ways, as "...the socio-spatial patterns of ableist values are etched across the city in numerous ways, forming a type of architectural apartheid."[41]

However, while many cities currently fail to deliver suitable living, social and working environments for PWD in practice, **cities can nonetheless be considered a space of opportunity for disability inclusive development if managed properly by local and regional government**. An immediate advantage is that the density of urban areas means that there are likely to be people with specific shared impairments and associated needs living in closer proximity. At the same time health facilities and other relevant infrastructure and services are often more concentrated in urban areas.[42] For example, in relation to medical disability services and access to assistive technology, major rehabilitation centres are usually located in urban areas.[43]

32. L.W. Isaksen et al, 2008. Global care crisis: a problem of capital, care chain, or commons? *American Behavioral Scientist,* 52(3), 405-425.

33. Q. Wodon & C.M. Blackden (Eds.), 2006, *Gender, time use, and poverty in sub-Saharan Africa* (The World Bank).

34. N. Folbre, 2006, Measuring care: Gender, empowerment, and the care economy. *Journal of human development,* 7(2), 183-199.

35. M. Oelz, 2014, The ILO's Domestic Workers Convention and Recommendation: A window of opportunity for social justice. *International Labour Review,* 153(1), 143-172.

36. Tronto, 1998, "An ethic of care."

37. World Health Organization, 2011. *World Report on Disability 2011.*

38. For the United States: G. Zhao et al, 2019, Prevalence of Disability and Disability Types by Urban–Rural County Classification—US, 2016. *American journal of preventive medicine,* 57(6), 749-756. For China: X. Peng et al, 2010, Ageing, the urban-rural gap and disability trends: 19 years of experience in China-1987 to 2006. *PloS one,* 5(8), e12129. For India: S.G. Kumar et al, 2012, Disability and rehabilitation services in India: Issues and challenges. *Journal of Family Medicine and Primary Care,* 1(1), 69.

39. Peng et al, 2010, «Ageing, the urban-rural gap and disability trends.")

40. J. Walker et al, 2020a, *Country Capacity Assessment for Assistive Technologies: Informal Markets Study, Sierra Leone,* Global Disability Innovation Hub Report (AT 2030 Programme, GDI Hub, London).

41. A. Hamraie, 2013, Designing Collective Access: A Feminist Disability Theory of Universal Design. *Disability Studies Quarterly,* 33(4): 232.

42. Alice Sverdlik, 2011, Ill-health and poverty: a literature review on health in informal settlements, *Environment & Urbanization,* 23(1): 123–155.

43. World Health Organization, 2011. *World Report on Disability 2011.*

4. Urban interventions and disability

Thinking about PWDs' particular experience of cities, it is clear that different approaches to governing and intervening in urban areas will affect the interests of PWDs in positive or negative ways. This relates both to urban governance practices more generally, and to specific urban interventions related to disability.

On the one hand, existing mainstream approaches to urban development affect the lives of PWD in particular ways. For example, current widespread policies of financialization of urban real estate and infrastructure has intensified urban inequalities which, given the strong association of disability with poverty, is likely to disproportionately impact the living conditions of PWD and their households.[44] At the same time, the frequent failure of urban governance to engage with and provide for citizens living in conditions of informality[45] means that PWD who lack formal evidence of citizenship status (for example, identity cards or proof of residency) are often unable to access the support that they should have a right to. Walker et al give the example of a social policy systems in Mumbai whereby children with disabilities living in rental housing in informal settlements were unable to register as disabled in order to access free health insurance and travel subsidies, because their households were unable to secure ration cards as the necessary proof of residence.[46]

In addition to mainstream urban governance processes, specific disability interventions also affect PWDs' experiences of cities. A key impact on the lived experiences of PWD in cities has related to the fact that historically, in many contexts, the provision of care for PWD has been largely in specialist institutions resulting in spatial segregation (for example, through specialist residential schools or for the deaf or blind, or residential institutions for people with psychosocial disabilities).[47] In response, and **in an effort to have more disability inclusive cities, the alternative of Community Based Rehabilitation (CBR) has increasingly been proposed as a means of meeting the support needs of PWD in mainstream communities and institutions** (for example, schools).[48] CBR can be seen as part of a wider impetus towards disability inclusive development in cities. This has been promoted through a range of institutional and networks, including the Global Network on Disability Inclusive and Accessible Urban Development (DIAUD),[49] the Eurocities Inclusive Cities for All Campaign, or the Inter-American Development Bank (IDB) Inclusive Cities institutional initiatives.

***Accessibility* is arguably a core component of all these initiatives.** This reflects the emblematic focus on accessibility in disability rights campaigns, and its prominent place in the CRPD, which specifies PWDs' rights of access "to the physical environment, to transportation, to information and communications, including information and communications technologies and systems, and to other facilities and services open or provided to the public" (CRPD Article 9.1). At the same time there is an increasing push to evaluate the impact of such networks on the realisation of inclusive cities, a challenging task given the complex and multifaceted nature of disability inclusion in cities, and the fact that "disability inclusion gets lost in overall inclusion dimensions."[50] Examples of such tools include UNESCO's assessment tool for inclusive cities which has been trialled in Indonesia or a proposed Disability Inclusion Evaluation Tool for cities which has been trialled in two European cities.[51]

In terms of research and scholarship to support interventions towards disability inclusive cities, there is a wide body of literature concerned with the spatial dimensions of accessibility, including building and infrastructure design, often under the banner of Universal Design, as well as a substantial body of work on accessibility of transport infrastructure.[52] **This focus on urban design is not uniquely related to physical accessibility but has also been linked to an ethics of care.[53] In this view, designing is a process that should (but often does not) involve care:** "Care is also present in the contrasting, positive, disposition that directs designers to engage with people dependent on the built environment, and to discuss, evaluate and respond to their vulnerabilities, desires and needs."[54]

44. S. Fainstein, 2016, Financialisation and justice in the city: A commentary. *Urban Studies*, 53(7), 1503-1508. / R. Yeo & K. Moore, 2003, Including disabled people in poverty reduction work: "Nothing about us, without us". *World Development,* 31(3), 571-590.

45. A. Roy, 2005, Urban informality: Toward an epistemology of planning. *Journal of the American planning association*, 71(2), 147-158. / E. Dagnino, 2007, Citizenship: a perverse confluence. *Development in practice*, 17(4-5), 549-556.

46. Walker et al, 2013, "Gender, difference and urban change."

47. C. Kliewer & S. Drake, 1998, Disability, eugenics and the current ideology of segregation: A modern moral tale. *Disability & Society,* 13(1), 95-111.

48. S. Deepak et al, 2014, An emancipatory research on CBR and the barriers faced by persons with disabilities. *Disability and rehabilitation,* 36(18), 1502-1507.

49. See https://cities4all.org/compact/

50. N. Rebernik et al, 2020, Measuring Disability Inclusion Performance in Cities Using Disability Inclusion Evaluation Tool (DIETool). *Sustainability*, 12(4): 1377.

51. UNESCO, 2017, *Assessment Tool for Inclusive Cities in Indonesia* (United Nations Educational, Scientific and Cultural Organization Jakarta Regional Science Bureau for Asia and the Pacific). / Rebernik et al, 2020," Measuring Disability Inclusion Performance in Cities Using Disability Inclusion Evaluation Tool."

52. Hamraie, 2013, "Designing Collective Access." / A. Hamraie, 2017, *Building access: Universal design and the politics of disability* (U of Minnesota Press). / J. Aarhaug & B. Elvebakk, 2015, The impact of Universally accessible public transport–a before and after study, *Transport Policy*, 44, 143-150.

53. C. Bates et al (Eds.), 2016, *Care and Design: bodies, buildings, cities* (John Wiley & Sons).

54. R. Imrie & K. Kullman, 2016, Designing with care and caring with design. In Bates, C., Imrie, R., & Kullman, K. (Eds.). *Care and Design: Bodies, Buildings, Cities* (Chichester: Wiley Blackwell): 8.

However, Terashima and Clark argue that while there has been an extensive focus on the implications of urban *design* for disability, research and interventions to make built environments more inclusive are rarely extend to areas of urban *planning* beyond questions of physical design of buildings and infrastructure.[55] This lacuna continues despite the reality that wider spatial planning also has an impact on PWD. For example, at the scale of city spatial planning "barriers in obtaining employment due to mobility restriction could be reduced if places of work and places of residence are closer in proximity and connected with accessible transportation infrastructure."[56] As will be explored below, one potential for a stronger focus on urban planning dimensions of inclusive cities could be related to a focus on planning the urban spatial distribution of infrastructures of care for PWD, such as the spatial distribution of social services or medical rehabilitation facilities.

The other prominent focus of efforts to make urban governance more disability inclusive, which is perhaps more related to the question of planning, is a concern with supporting PWDs' citizenship practices and their active involvement in development processes. In cities, this includes the roles of PWD in the design of social infrastructure such as transport and public space or urban governance as well as planning areas of development which could have a potential role in caring strategies, such as Information and Communication Technology (ICT) agendas and associated 'smart cities' strategies.[57] **This is in keeping with the disability rights movement (DRM)'s strong advocacy for recognising and supporting the agency of PWD in leading strategies for PWD and their communities, epitomised in the slogan** *Nothing About Us Without Us.*[58]

5. Caring, disabilities and cities: Some entry points for LRGs

Patterns in the experience of PWD in cities, as well as the particular political resonance emancipatory model care for PWD, suggest that there could be a number of ways in which local and regional governments (LRGs) can promote caring practices that support both PWDs in cities, and those with whom they are in relationships of care.

Given the DRM principle of *Nothing About Us Without Us* **a general principle for urban interventions to support care and inclusive cities should be the active role of PWD, older people and AT users in prioritising, formulating and governing such interventions.** This commitment is reflected in the Cities for All Global Compact which commits to (para 3): "Promote the full and effective participation of all persons, particularly persons with disabilities and older persons, in cities and urban planning strategies". Similarly, the UNESCO Assessment Tool for Inclusive Cities includes a focus on PWDs' political participation, including factors such as the representation of PWD/ OPDs in key decision-making for a, the accessibility of public buildings, the reflection of PWD's needs in municipal plans, and PWD's access to elections.[59]

In addition to the principle of PWD's leadership in decision-making about interventions to promote care for PWD more generally, this paper will explore three entry points to foster caring cities for PWD:

→ extending access to social rights for care to PWD in contexts of informality;

→ supporting (paid and unpaid) care work; and

→ ensuring the accessibility of infrastructures of care.

55. M. Terashima & K. Clark, 2021, The precarious absence of disability perspectives in planning research. *Urban Planning*, 6(1), 120-132.

56. Terashima & Clark, 2021, "The precarious absence of disability perspectives in planning research,"127.

57. F*or public spaces:* C. Baldwin & L. Stafford, 2019, The role of social infrastructure in achieving inclusive liveable communities: voices from regional Australia. *Planning Practice & Research*, 34(1), 18-46. / *For urban governance:* D. Bezmez, 2013, Urban Citizenship, the Right to the City and Politics of Disability in Istanbul. *International Journal of Urban and Regional Research*, 37(1), 93-114. / *For smart cities*: G. Szaszák & T. Kecskés, 2020, Universal Open Space Design to Inform Digital Technologies for a Disability-Inclusive Place-Making on the Example of Hungary. *Smart Cities*, 3(4), 1293-1333.

58. J.I. Charlton, 2000, *Nothing about us without us: Disability oppression and empowerment* (University of California Press).

59. UNESCO, 2017, *"Assessment Tool for Inclusive Cities in Indonesia."*

5.1 Extending access to social rights for care to PWD in contexts of informality

While, as discussed earlier, density of population, and of infrastructure and services should be an advantage for care provision to PWD in urban areas, this is not necessarily the case in practice. PWD are likely to be caught up in wider urban patterns of inequality regarding care services. For example, research into healthcare provision more generally suggests that urban density does not lead to more accessible provision for low-income citizens or residents of informal settlements, as, "Largely due to unresponsive local governance, low-income urban residents may enjoy few if any health advantages over their rural counterparts" in terms of access to health services and infrastructure.[60]

A key challenge for responsive urban governance around care provision is reaching urban citizens living in contexts of informality. If we consider informal citizenship as the state of lacking the registrations and official recognition that entitles people to the full range of citizenship rights for which they would otherwise be eligible (e.g., the right to social services, legal protection, or democratic participation),[61] then lack of formal citizenship rights is a key barrier to accessing care.

The findings of the AT2030 research project show some of the ways in which that lack of formal citizenship rights can act as a barrier for PWD to access care services, including, as a specific focus of the research, the right to assistive products and associated services such as assessment, fitting, user training, maintenance and repairs.

In the case of Freetown, Sierra Leone, three-quarters of the total urban population lives in areas classified as slums, and the limited reach of state governance and services means that the majority of the urban population can be considered to live in a state of informal citizenship. As a result, rights in policy do little to guarantee access to caring services for many PWD in practice. As an example, whilst the Sierra Leone 2011 Disability Act states that PWD have the right to free healthcare, according to our research the enforcement of this right

An AT user being fitted with a prosthetic at the Jamkesus in Yogyakarta by the NGO Yakkum which provides Prosthetics and Orthotics and associated services (Source: Julian Walker)

at public hospitals is rare, mostly due to hospitals' limited financial resources and the de facto practice of cost recovery from all service users, including PWD. At the same time, as in other contexts of scarcity, people in Sierra Leone rely heavily on informal connections—referred to in Krio as *sababu*, or "those you know"—to access their rights, as well as opportunities, goods, and services. But whilst poverty increases the need for such influence, it decreases access to it at high levels, exacerbating exclusion.

In Indonesia, taking the case of the city of Banjarmasin, while state interventions to provide care for PWD have more reach than in Sierra Leone, access to state care services generally requires evidence of citizenship through a range of registrations such as a Kartu Keluarga (family card) an ID card (KTP) or a KIS red card which is needed for subsidised BJPS (national health insurance) provision. However, there are several reasons why people may lack these forms of registration, including:

60. Sverdlik, 2011, "Ill-health and poverty," 123.

61. Dagnino, 2007, "Citizenship."

→ Complex bureaucracy - accessing the KIS red card, to secure eligibility for free Assistive Product and other support schemes from the municipal Social Department involves up to 12 steps of registration (and the process differs by municipality).

→ Particular difficulty for groups such as PWD, older people, or very poor people to physically access government offices where registrations are conducted.

→ Administrative barriers to registration, such as applicants having unclear residential addresses, illegal or informal tenure status, or lacking a birth certificate. Another administrative barrier is that, even if people are registered with one local government, because of local autonomy in public service provision, some groups of migrants who live in cities cannot access certain local public services because their ID cards do not match their current place of residence. Officially, Indonesians can register as residents after living somewhere for more than 6 months, but many migrants fail to do this and some cities (e.g., Jakarta) do not allow for temporary registration.

City residents in Yogyakarta, Indonesia registering for access to assistive technology services at the Jamkesus. (Source: Julian Walker)

In terms of the scale of exclusion from these schemes, taking the case of Banjarmasin as an example, the AT2030 project collected data from 2,046 individuals using the WHO Rapid Assistive Technology Assessment (rATA) in two low-income settlements. However, as part of their data collection process, the rATA survey data collectors excluded short-term renters who had not registered their domiciles in the two communities surveyed. This amounted to 5-10 per cent of the total residents of the two low-income urban settlements surveyed. This was confirmed as a typical proportion by one of the RT leaders leader (RTs are the smallest urban administrative residential unit) interviewed during the study, who explained that RT leaders cannot put members of such unregistered households forward to be beneficiaries of schemes for PWD carried out by the municipality or Social Department (for example donations of free Assistive Products on International Disability Day). Beyond the exception of such unregistered migrant households, RT leaders have a high level of autonomy in deciding who to include on the list of low-income residents eligible for the red KIS card. However, they do not receive any formal training to guide their decision-making about disability, poverty and support needs, and must rely on their local knowledge and familiarity with their neighbours. Moreover, official criteria for poverty determining eligibility for the red KIS card —including not having a vehicle, covered floor, or TV—are not applicable in many communities. In Banjarmasin, for example, using these criteria, almost no household in the city would be classified as poor, despite the reality that many are.

Such processes can conspire to exclude PWD living in contexts of formality from states systems of care support. Nonetheless, efforts are made in Banjarmasin to ensure that PWD are able to register and formalise their citizenship status to access their rights. For example, in Banjarmasin, in every RW (the second level of administrative unit), there is a social worker (PKH assistant) in the social department who helps red KIS applicants to register. Another promising initiative to address administrative bottlenecks that exclude PWD from state care services is the Jamkesta scheme in Yogyakarta, Java (see Box 1).

Jamkesta: Streamlining public policy to enable better access for low-income citizens to AT

The Jamkesta scheme was set up in the special province of Yogyakarta in collaboration with the city and regency (provincial) governments to make AT more accessible to users. It provides health insurance to poor people who are not covered by Jaminan Kesehatan Nasional (National Health Insurance) with a special focus on PWD and AT users. It is based on the Pergup (Governors Regulation) No. 50 and 51 of 2014, which was developed with active participation by the provincial Disability Committee. The Pergup compels the use of budgets for AT, but it initially only covered a small percentage of the cost of purchasing AT, leaving AT out of reach for low-income AT users. A 2017 revision changed the coverage to 80 per cent and also made repairs eligible for reimbursement.

In other provinces in Indonesia, efforts to subsidise poor people's access to the Indonesian health insurance card (KIS) is through the Jamkesprov at the provincial level and Jamkesta at the city level. Because Yogyakarta is a special administrative region, however, the province does not have to align itself with the KIS system and has developed its own approach.

An important part of the Jamkesta scheme is the Jamkesus, a public event which acts as a one-stop shop for AT provision and involves state actors working with NGOs, private sector partners, and volunteers. The Jamkesus is held at least twice per year in each city or regency. At the Jamkesus events, low-income AT users can go through the steps to register as a beneficiary, including medical assessment, AP prescription, fitting, and training, all in one place and in one day.

5.2 Supporting (paid and unpaid) care work

As discussed earlier, care is a critical resource for PWD. **However, if care services are to be emancipatory, supporting the agency and autonomy of PWD, as well as fostering respectful relations between carers and PWD and for care of this nature to be delivered, carers need to be publicly valued, rewarded, and have access to relevant skills and capacities.** In practice, care workers for PWD and older people, and in particular migrant care workers, are often exposed to devalued and precarious work[62] which has impacts both on themselves and on those for whom they care. **Accordingly, LRGs have a role to play in supporting the value and skills development of carers, including both unpaid carers in the community and household, and professional care workers.**

Key areas of support that LRGs can give to unpaid community level care workers (in many contexts, predominantly women working on a voluntary basis) include providing training, venues and resources to support their work and also promote the social value of voluntary care work. This can include recognising the value of care work by promoting it as a vehicle for opportunities for greater involvement in local decision-making fora.[63] This kind of support implies recognising the range of community-based organizations providing care and other support for PWD. For example, the AT2030 programme found in Sierra Leone that religious organizations, and organizations of the urban poor play a key role in providing care services, or access to assistive products, to PWD. However, in the context of stigma around disability, and a lack of disability knowledge in such organizations may limit the quality of such support – this was acknowledged by the leadership of FEDURP (the Federation of the Urban and Rural Poor, a Slum Dwellers International Affiliate) in Freetown. Therefore, **a key role of LRGs can be to support such community-based care work with knowledge and information resources,** and also build the capacity of OPD such as SLUDI (the Sierra Leone Union on Disability Issues) or the Association of Indonesian Disabled Persons (PPDI) in Indonesia to guide community-based care strategies.

Another important entry point for LRGs into community care work for PWD is in supporting unpaid carers in the family and the household. While financial support is not sufficient without wider interventions, one promising route is through social protection schemes which provide financial support to address the extra costs for care that have to be absorbed by many households with members who are PWD, such as the Disability Grant, or Dependency Grant for carers of children with disabilities in South Africa, or social protection schemes in Zambia and Uganda that are not disability specific, but consider disability as a household eligibility criteria;[64] or schemes such as Australia's new National Disability Insurance Scheme which affords PWD and their households more choice and control over, and ability to plan, the care services that they need.[65] **The LRGs role in administering or devising city level social protection therefore creates a space both for directly allowing PWD and their households to commission care services or to support the unpaid care work of PWD's household members.**

On the other hand, given that many PWD rely on professional care workers, another key role is to support professional carers and extend decent working conditions to care workers. For care workers working with PWD, a key concern is that they have the skills to deliver care that supports the autonomy and self-determination of PWD.[66] This requires facilities for appropriate skills development. Examples of such facilities at the city level in Indonesia which were explored in the AT2030 project include the municipal 'balai' (rehabilitation/ training centres') run by the Ministry of Social Welfare. In this system, 19 specialist national balai are complemented by a far greater number of municipal balai (in Central Java, for example, there are 54 municipal balai). As well as providing care services for PWD, including health care and AT services, balai provide training both for disability care professionals and for PWD (including training for example AT use, but also in other areas such as vocational training).[67] On the other hand, given that much paid care work for PWD and older people is provided

62. H. Jönson & A. Giertz, 2013, Migrant care workers in Swedish elderly and disability care: are they disadvantaged? *Journal of Ethnic and Migration Studies*, 39(5), 809-825.

63. J. Walker, 2013, Time poverty, gender and well-being: lessons from the Kyrgyz Swiss Swedish Health Programme. *Development in Practice,* 23(1), 57-68.

64. M. Schneider et al, 2011, Reflections on including disability in social protection programmes. *IDS Bulletin*, 42(6), 38-44.

65. M. Kendrick et al, 2017, Australia's national disability insurance scheme: looking back to shape the future. *Disability & society*, 32(9), 1333-1350.

66. Morris, 2011, *"Rethinking disability policy,"* 11.

67. J. Walker et al, 2020b, *Country Capacity Assessment for Assistive Technologies: Informal Markets Study, Indonesia* (Global Disability Innovation Hub Report, AT 2030 Programme, GDI Hub, London).

not by specialist disability care workers, but by general domestic staff,[68] another potential area of intervention for LRG is to govern, support and build capacity of domestic workers and the domestic work sector in line with ILO convention 189. Such capacity building for domestic workers' care giving roles could fit int existing schemes – for example the Vocational Training Program for domestic workers conducted by the Ministry of Labour, Employment and Social Security of Argentina, which has been supported by the ILO.

Another important role of LRGs is to support the role of OPDs in guiding priorities and governing implementation for urban care institutions in line with the principles of disability user-led care services.[69] Leading on user led care services could be a key role for umbrella OPDs, such as SLUDI (the Sierra Leone Union on Disability Issues) or the National Commission for Persons with Disabilities in Sierra Leone or the Association of Indonesian Disabled Persons (PPDI) in Indonesia, but this requires institutional mandate and support from appropriate municipal authorities.

5.3 *Ensuring the accessibility of infrastructures of care*

The relationship between infrastructure and care encompasses both: the extent to which the processes of infrastructure design and provision cares for and responds to the priorities of users, including PWD, and; the extent to which infrastructure of care (for example health services, social facilities, accessible transport infrastructure, rehabilitation centres, supported housing, or inclusive education centres) are accessible.

In terms of the first question, the concept of universal design aims to ensure than urban infrastructure is relevant and useable for all. The CRPD (article 2) defines universal design as "the design of products, environments, programmes and services to be usable by all people, to the greatest extent possible, without the need for adaptation or specialized design". **The process of universal design implies care – for the design process and for the needs of infrastructure users,** stressing "the importance of attending to the 'fits' and 'misfits' between people and built form, as well as the politics and ethics implicated in these."[70] **While universal design for a variety of users with different and at times competing needs remains a challenge,[71] LRGs should nonetheless adhere to its principles to ensure the urban design keeps inclusion in sight as an overarching priority.**

In terms of the second question, if we take infrastructures of care to mean the facilities and built environments that support key care services, related to health, or other aspects of personal well-being prioritised by PWD, accessibility, particularly of specialist

A participant in the AT2030 Research Project in Freetown, whose wheelchair was acquired second hand, with no access to assistive technology care services such as fitting or training (Source: Angus Stewart)

infrastructure with small user groups spread across the city population, presents a key concern. There is a substantial literature on infrastructural inequalities in cities which often maps infrastructural inequality across cities onto the experience of informality and poverty.[72] The frequent association of disability with poverty means that PWD may experience such infrastructural inequality in interlocking ways, both through the wider exclusion low income settlements from access to key urban infrastructure, and through the failure to provide community based infrastructure that is inclusive of the needs for PWD, or specialist disability infrastructure that meets specific needs (for example, impairment related rehabilitation services, or communication and education facilities that are tailored to the needs of hearing or visually impaired people, or PWD with specific cognitive support needs). Box 2 explores the experience of unequal access to health infrastructure for PWD in Freetown, Sierra Leone.

68. B.S. Yeoh & S. Huang, 2009, Foreign domestic workers and home-based care for elders in Singapore. *Journal of Aging & Social Policy*, 22(1), 69-88.

69. C. Barnes & G. Mercer, 2006, *Independent Futures. Creating user-led disability services in a disabling society* (Policy Press, Bristol).

70. Imrie & Kullman, 2016, "Designing with care and caring with design," 6.

71. Y. Afacan & H. Demirkan, 2010, A priority-based approach for satisfying the diverse users' needs, capabilities and expectations: a universal kitchen design case. *Journal of Engineering Design*, 21(2-3), 315-343.

72. See for example: S. Graham & S. Marvin, 2001, *Splintering urbanism: networked infrastructures, technological mobilities and the urban condition* (Psychology Press). / C. McFarlane, 2010, Infrastructure, interruption, and inequality: urban life in the global South. In Graham (Ed.) *Disrupted cities: when infrastructure fails*, 131-144, (New York: Routledge).

Accessibility of Healthcare for PWD in informal settlements in Freetown

The AT2030 project worked in four communities in Indonesia and Sierra Leone, conducting research with PWD, AT users, and some non-disabled community members to identify their aspirations and how they are able to pursue them. In one of the communities, the hillside informal settlements of Dworzark in Freetown, Sierra Leone, participants selected Affordable and Accessible Healthcare as the shared aspiration that they felt would be most transformative for the lives of PWD and AT users involved in the research. This aspiration responded to the existing inaccessibility of health services for residents of Dworzark, which were even more pronounced for PWD and AT users.

One of the key challenges that participants highlighted were the very limited water and sanitation infrastructure in the settlement, which causes problems both for PWD's self-care and for their carers to engage in daily hygiene practices. Another issue related to health care services was that there is only one health centre in the entire settlement of Dworzark, which has very limited capacity to serve the settlement population (estimated at 16,500). As a result many residents instead attend hospitals in the city centre, which are at a significant distance from the community. This creates an additional barrier to accessing health services, implying additional travel time, difficulties and expenses, and is a particular problem for many PWD who are unable to, or find it difficult to use public transport options, especially as many PWD told us that they are often stigmatised and mistreated by transport providers. Furthermore, while the city has a range of public and private hospitals, these are often unaffordable to PWD on low incomes, and often not designed accessibly (at the time of the research the National Commission for Persons with Disabilities was, in response to this problem, doing an Accessibility Audit at the Connaught Hospital).

The problem of accessibility of health infrastructure is even more extreme for AT users who need to access the specific services offered by the city's only National Rehabilitation Centre (NRC). One of the AT2030 research participants comes from a land occupation in the city centre of 50 households, all headed by wheelchair users from the organization HEPPO (Help Empower Polio People Organization). She explained that to get to the NRC in the neighbourhood of Aberdeen, which is the only specialist prosthetics and orthotics care provider in the city, she and the other residents of the HEPPO occupation cannot take public transport. Minibus and keke (motorbike tricycle) drivers usually refuse to accommodate wheelchair users and it is not possible for them to use the other main option (motorbike taxis). Instead, they have to push their wheelchairs the whole way to the NRC (two hours in each direction). As a result, few of them use the NRC and most buy their own wheelchairs from the second-hand markets in the city centre (Kissy Road) without any of the related care services (medical assessment, fitting, training). Given the serious problems of morbidly and mortality resulting from ill-fitting wheelchairs,[73] the provision of wheelchairs without care services is a serious problem.

The experience of PWD and AT users in Freetown with reference to access to health care in Box 2 highlights the need for LRGs to use the urban planning tools and processes at their disposal to promote affordable and decentralised care services and infrastructure throughout cities, including within low-income and informal settlements. At the same time, this should be supplemented by planning efforts to coordinate accessible transport infrastructure with essential care services and facilities for PWD.

Given the importance of PWD's agency in planning of care services, and the OPD principle of *nothing about us without us,* planning processes concerning infrastructure of care should reflect the priorities and lived experiences of PWD and their organizations. This can be promoted through a number of avenues.

On the one hand participatory data collection with PWD can act as an input to the planning of disability inclusive cities, to foreground PWD's lived experiences and perspectives, as with the initiative conducted by the NGO Kota Kita in Banjarmasin, Indonesia, with the Banjarmasin City Government and the Network of Mayors for Inclusive Cities.[74] Secondly, **efforts can be made to ensure the participation of PWDs and OPDs in participatory urban planning initiatives such as participatory budgeting, deliberative health councils or participatory urban planning initiatives.**

73. T. Øderud, 2014, Surviving spinal cord injury in low income countries. *African Journal of Disability*, 3(2).

74. See https://www.kotakita.org/project-disability-inclusive-banjarmasin.html

6. Conclusion

This chapter has argued that, while cites have often historically been spaces of exclusion, segregation and inequality for PWD, the density of urban spaces, the scope for generating mainstream and specialist urban infrastructure at scale, and the fact that cities are a places of encounter and politicisation for PWD, means that cities should be a site of opportunity for disability inclusive development.[75] Such disability inclusive development should include strategies to promote the autonomy and voice of PWD and care for PWD as mutually supporting objectives. **Focusing on inclusive development in cities will not only benefit the wide range of citizens who experience disability across their life courses, but also other groups of urban citizen whose needs may not be routinely reflected in mainstream urban planning** (for example, pregnant women negotiating urban spaces, or migrants not speaking local languages who need to access public information and communication). This requires an emancipatory mode of care that is led by the priorities of PWD. To this end, while recognizing that the boundaries of disability are unclear, LRGs should work with people who self-define as disabled, including through their organisations (OPDs), to understand PWDs' priorities and experiences as care service users and define urban strategies for disability care accordingly. Finally, this paper has proposed three specific entry points for LRG to support emancipatory care for PWD: extending care services in the context of informality; supporting and valuing paid and unpaid carers; and ensuing the accessibility of infrastructure of care that are prioritised by PWD.

75. IADB (Inter-American Development Bank), 2021, Cities as Spaces of Opportunities for All: Building Public Spaces for People with Disabilities, Children, and Elders, editor, Nora Libertun de Duren., *IDB Monograph*, 859.

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